Letters

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Doctors write on patients' eye view of quality

Do patients want first class or economy services?

EDITOR—Rayner's wish list in her personal view about a patient's eye view of quality in the NHS contains nothing that I would not want for myself as a patient, but her article fails to address issues of resourcing, except where she mentions the "sizeable fees collected" by alternative practitioners.[1]

In a crowded surgery recently I spent half an hour with an anxious patient exploring the patient's concerns about forthcoming hospital treatment. I met that patient's needs and wants, and as a result my surgery ran late and other patients in the waiting room grumbled. This sort of thing happens all the time and cannot be solved by bringing the patient back at a quiet time because there aren't any such times. In any case, that would hardly satisfy Rayner, who wants us to be responsive to our patients' anxieties at the time when they are expressed.

We cannot please everyone all the time or guarantee always to satisfy such a comprehensive wish list within existing time pressures and limited resources. British general practitioners know how to provide a quality service, and usually do, but are compelled to provide a high volume economy service in which there is no limit on demand. To make it through the day we sometimes have to compromise on the niceties of life, unlike the alternative practitioners, in whose case the money comes with the patient.

I recently paid around £1000 to fly economy class to New Zealand. It was OK but cramped, and I didn't like the films. A first class ticket would have been much more agreeable, and, like Rayner's vision of the NHS, would have cost about twice as much.

If the Patients Association wishes to make a useful contribution to the debate on quality I suggest that it gets together with the GP Committee and starts a postcard campaign, getting patients to write to their MPs. These patients should say that they are willing to pay their share of whatever it takes to get health spending in the United Kingdom up to the European (or better still, the Franco-German) average.

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1 Rayner C. A patient's eye view of quality. *BMJ* 1999;319: 525. (21 August.)

Demand is too great for GPs to provide patients with longer appointments

EDITOR—I was always taught at school to compare like with like: comparing oranges with lemons is meaningless. Likewise Rayner's comments about alternative practitioners are unfair: "A wide range of untrained individuals … collecting sizeable fees in exchange for all sorts of nonsense."[1] I know several alternative practitioners, and they do not match this description. They are honest people doing their best to help patients in distress. They may have different perspectives from traditional doctors, but their aim is the same: we both work to help alleviate human suffering. Both traditional doctors and alternative therapists work to the best of their ability in any given situation. Mostly, both orthodox and complementary practitioners value the therapeutic relationship over technical prowess.

The problem for traditional doctors at present is that demands are rising because of increasing expectations and increasing public panic over, for example, a few cases of meningitis and increased awareness of the importance of symptoms such as testicular or breast lumps. The media have played their part in informing patients, but all their articles end with: "If in doubt see your GP."

With increased demand and no more of me today than there was yesterday, I am increasingly pushed into get-through-the-day medicine rather than thoughtful relaxed consultation. My colleagues elsewhere are under similar strain. If some of the extra demand for health care in all its forms goes in the direction of alternative therapists this saves the NHS some money and reduces the pressure on us.

Until more resources are available to allow NHS doctors more time to talk with our patients (and on the whole we enjoy doing this), we will not be able to match the more relaxed consultations that our colleagues in alternative medicine can enjoy. A reappraisal of what we can be expected to deliver on the NHS is long overdue, but I doubt that any politician has the honesty or bravery to attempt such an exercise.

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Patients must "get real"

EDITOR—Rayner does not compare like with like.[1] The huge advantage that alternative therapists have is time. They can work at any speed that they choose and accept only cases that they want.

As a consultant in the NHS, I see between four and eight patients an hour, depending whether they are new or review patients. Often it is the review patients who take the most time, and they are allocated 7.5 minutes. The information that we need to share is often complex. We would love to work at the relaxed pace of the alternative therapists, but it would be impossible to continue to provide an acceptable service to the public: my waiting list would stretch into years.

It is unhelpful of Rayner to suggest that we can provide a service that depends so much on time that we clearly do not have[1]; most of us try as hard as we can with the limited time available. Rayner should also remember that we are usually supervising other doctors and nurses, and teaching students and doctors in the clinics and on the wards. We would ask Rayner to "get real."

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Longer consultation time that patients wish for is not available in NHS

EDITOR—Most of the items in Rayner's summary of patients' views are achievable in the NHS.[1] In her final point, however, she compares the perceived level of communication in the NHS with that of alternative therapists. Her criticism is that, unlike the NHS, alternative therapists have a "willingness to listen" and take the time to communicate more fully. This probably comes down to the time available in different clinics.

We carried out an audit to compare the time available for initial outpatient consultations by medical practitioners working in the NHS or the private sector and alternative therapists. For the NHS appointments, the medical records department and individual consultants were asked to state the time allocated in outpatients for new patients. Consultants were also asked about their appointments in private practice. A selection of alternative therapists was selected from the Yellow Pages and asked how long they allocated for a new patient. The alternative therapists approached included an acupuncturist, an aromatherapist, a medical herbalist, a chiropractor, a reflexologist, and a homoeopathic practitioner.

In our university teaching hospital, the time allocated for a new outpatient appointment is between 5 and 15 minutes; the time depends on individual consultants and the number of doctors available. This increases to 15-30 minutes in the private sector, although consultants here can allocate as much time as they find necessary for an individual patient. The alternative therapists all allocated between 60 and 90 minutes for a new patient/client appointment.

In the light of this perhaps it is not surprising that alternative therapists have the time to listen and to communicate with the patient. In the NHS, with such a superior service to offer, undoubtedly we should do the same. Within the current limitations, however, the time required is just not available.

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Summary of rapid responses

Six of the 11 responses to this personal view by Claire Rayner were from doctors working in primary care or academic general practice, and five were from specialists.[1] All reiterated the reality of the NHS—not enough time or money for doctors to communicate with patients as they would like.

N Kaushik challenges Rayner to spend a week in his ophthalmology department offering "her communicative skills to 50 patients … within a clinic of 3½ hours." J Kirwan, another ophthalmologist, estimates "a theoretical maximum of 4-5 minutes per patient to actually talk and listen. Clearly this is insufficient time to communicate as we would wish."

S Nimmo, a general practitioner, declares: "It is not for my benefit that I have to churn patients through in 5 minutes … I would love to be able to sit and listen to patients for 30 minutes…. But in today's increasingly consumer-led society, where demand equals need and instant gratification is king, I can't." He suggests that things might be different if the Patients Association emphasised patients' responsibilities as much as patients' rights and encouraged people to use the NHS appropriately.

J Foster describes the recruitment crisis in general practice and how many experienced general practitioners are leaving "unable to live up to the expectations of patients and themselves." She asks the association "to acquaint patients with the current limitations of the under-resourced NHS, so that they may have more realistic expectations of what can be achieved in a 10 minute consultation. Only when our list size is reduced can we spend more time with our patients."

J P Driver-Jowitt observes that both doctors and patients are unhappy. He suggests that "rather than trying to extract more ounce from health practitioners, the [Patients Association should try] to understand better how patients and practitioners could work in unison towards a common cause." Perhaps the association could look first at the needs of health professionals? "Only when there are signs to the doctors that these are being recognised, will the members begin to benefit in substance."

P Leigh points out that just as alternative therapists ration their caring by charging substantial fees, so doctors have no alternative to rationing "if the quality of [their] listening is to improve within existing cost limits…. Perhaps NICE will develop into an effective means of rationing all health care."

M Marshall concludes: "Quality of health care will only be addressed in a meaningful way when all the stakeholders agree to work together and make compromises. They will then need to question not only what they want but also what trade-offs they are willing to make."

1 Electronic responses. A patient's eye view of quality. *eBMJ* 1999;319 (www.bmj.com/cgi/eletters/319/7208/525). (Accessed 8 December.)

Effectiveness of rivastigmine in Alzheimer's disease

Participation in trials should be based on clinical uncertainty, not enforcement

EDITOR—The clinical relevance of new drugs in Alzheimer's disease has been much debated, and there is little dispute that we need improved trials in the disease.[1] Enrolment into trials, however, should be governed by clinical uncertainty.[2]

Bentham et al criticise recently published studies of rivastigmine and advocate support for studies such as the AD2000 donepezil trial.[3] We are concerned that some health authorities in the United Kingdom have stated that reimbursement for donepezil would be made only if patients were randomised into this trial. Presumably, following the lack of participation in the trial by many clinicians in the United Kingdom, the threat of non-reimbursement is an attempt to aid flagging recruitment.

Many clinicians have chosen not to be involved for good reasons. Part of the trial's complicated design seems to attempt to replicate the studies that formed the basis of regulatory approval. The manufacturers already have over 3000 patients with detailed controlled data over six months. The first three months of the trial, before rerandomisation, will not add to this assessment and may confuse rather than enlighten, especially given the use of only the lower, 5 mg dose. The Bristol activities of daily living scale may not have been the optimum choice of primary outcome measure[4]: we are not aware that it has been shown to be a reliable measure of change over time. Other instruments have been validated longitudinally and used in several hundred patients.

We believe that the Birmingham study is considerably underpowered. On the basis of the dependency scale, we calculate that 4000 patients treated for two years are needed to show with 90% power, and allowing for drop outs, a moderate difference of 20% in dependency for patients with mild to moderate Alzheimer's disease.[5] Extending the indications for which donepezil is approved by including vascular dementia is not a problem, but lack of characterisation of the disease at entry to the trial, especially without computerised scanning, is. A negative result is likely and could jeopardise the interpretation of existing data on the beneficial effects of donepezil, and other cholinesterase inhibitors, in Alzheimer's disease. We also query why free drug will not be provided.

The success of large simple trials has been built on the principle of uncertainty by consenting clinicians, not enforcement. Perhaps the authors could address some of these concerns; collectively we could turn this into a valid and relevant study. At present, the situation represents a threat to clinical freedom for many of us who are advocates of large simple trials; we are concerned that undue heed will be taken of the outcome.

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Competing interests: All the authors have been involved in the development of drugs for dementia (tacrine, donepezil, rivastigmine, and so far unlicensed products). This involvement has been at phase II/III/IV trial, protocol development, data analysis, and advisory board level, for which payment was made to their research units. RB, PP, DW, and RJ have received remuneration for consultancy, speaking, or attending symposia from major drug companies. None of the authors has affiliation with any one pharmaceutical company.

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Authors' reply

Editor—We agree with Bullock et al that improved trials of new dementia drugs in Alzheimer's disease are needed. Previous studies of donepezil have found moderate improvements in results of cognitive tests and a clinical impression of change—in highly selected patients—but have not shown worthwhile improvements in activities of daily living, non-cognitive symptoms, or the wellbeing of carers. AD2000 is assessing these more socially relevant outcomes among a clinically representative group of patients and is not replicating previous trials.

Neither is the AD2000 study underpowered. With just 800 patients randomised, it would have ample statistical power to confirm, or refute, even small differences in the important short term end points. The use of 5 mg donepezil for the first 12 weeks will not materially affect statistical power as 10 mg has not been established to be better than 5 mg.

Any clinically worthwhile longer term improvements will also be detected. The study by the consortium to establish a registry for Alzheimer's disease suggests that 25% of patients will reach one of the primary disability (not dependency) end points at one year, and there would be 90% power to detect a reduction to 15% with 800 patients.[3] Use of the Bristol activities of daily living scale[1] is appropriate because the scale is designed to detect clinically important differences, is validated against performance activities of daily living, and is sensitive to change.[2] Longer term treatment and follow up are planned, which will increase statistical power.

The lack of consensus on the clinical relevance of cholinesterase inhibitors emphasises the importance of obtaining more reliable evidence on their effectiveness. With 320 patients already randomised, from 25 centres, AD2000 is progressing well. Donepezil cannot be provided free because the manufacturers do not support this rigorous, independent evaluation. Lack of funds for the costs of treatment has been holding back recruitment, but the national subvention should help. It is understandable that some health authorities would prefer to target any extra resources on AD2000 rather than pay for haphazard, and uninformative, clinical use outside a trial. The debate about appropriate resource allocation for cholinesterase inhibitors would exist whether or not the AD2000 trial was being undertaken.

Finally, we welcome the authors' advocacy of large simple trials with eligibility based on uncertainty. On present evidence, there is uncertainty for all patients with a diagnosis of Alzheimer's disease (for which neuroimaging is not essential) over whether they will derive worthwhile benefit from donepezil. Further support for AD2000, to resolve these uncertainties, can only benefit patients.

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Accuracy of perceptions of hepatitis B and C status

Injecting drug users need vaccination against hepatitis B

Editor—Best et al give us useful information about drug users' perceptions of their hepatitis B and C status and, on the basis of this, recommend that clinicians should test all drug users for hepatitis B and C infection.[1] With respect to hepatitis B, however, they fail to mention a more important intervention—namely, immunisation against hepatitis B.

This oversight may partly stem from their failure to distinguish current from past infection. We assume (although they do not state) that by "positive for hepatitis B virus" they mean that the serum was positive for antibody to hepatitis B core antigen. Alone, this marker signifies infection at some time in the past and probable protection against subsequent infection. The marker of active infection (and therefore infectiousness) is hepatitis B surface antigen. Among those infected by drug use one would expect less than a tenth of those with antibody to hepatitis B core antigen to also be positive for hepatitis B surface antigen.[2]

Drug users who are positive for antibody to hepatitis B core antigen but negative for hepatitis B surface antigen might correctly be informed that they are not at risk of the sequelae of chronic hepatitis B. They might also be told that they are no longer at risk of hepatitis B and that vaccination is unnecessary. Commercial assays for antibody to hepatitis B core antigen may, however, result in false positive test results,[3] and patients at risk may therefore be denied the protection of a safe and effective vaccine. A positive result of a test for antibody to surface antigen is a more reliable marker of immunity.

Before recommending widespread testing of drug users we need to know whether knowledge of hepatitis status changes behaviour. In the study of Best et al a high proportion of drug users had previously been tested for hepatitis B and C. Despite this the high prevalence of both infections and the incorrect self reporting of status suggest that testing may have little effect on behaviour. Meanwhile, the number of cases of acute hepatitis B among drug users is increasing,[4] and, despite the availability of a highly effective vaccine, too few have been offered that intervention. We recommend that hepatitis B vaccine be offered to drug users at every opportunity and not be delayed while results of antibody testing are awaited.

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1 Best D, Noble A, Finch E, Gossop M, Sidwell C, Strang J. Accuracy of perceptions of hepatitis B and C status: cross sectional investigation of opiate addicts in treatment. *BMJ* 1999;319:290-1. (31 July.)
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4 Acute hepatitis B in injecting drug users is increasing as initiative to improve vaccination coverage begins. *Commun Dis Rep CDR Wkly* 1999;9:183, 186.

Results require further clarification

Editor—We agree with Best et al that knowledge of hepatitis B and C viral status is important for injecting drug users, in the context of both the users' health and the health of others.[1] The authors' short report, however, provided little clarification of the issues concerned.

The authors describe applying "virus tests" for hepatitis B and C to the blood they collected. Was the blood actually tested for hepatitis B and C virus (antigen)? As one response in the *eBMJ* has already pointed out, this is unlikely given the prohibitive cost of the nucleic acid amplification assays involved.[2] More probably the blood was tested for serological markers (antibody) indicative of past exposure. Results of such tests require careful interpretation, and confusion is still widespread.[3]

Users were asked about their "viral status." Again it is unclear if this refers to antigen or antibody status. The two have

very different implications in individual and public health terms, and between the two viruses. Roughly three quarters of people infected with hepatitis C virus will become chronic carriers, in contrast to less than a tenth of those infected with hepatitis B virus. Previously tested users who were antibody positive but antigen negative and who described themselves as "negative" were arguably correctly interpreting their status, at least for hepatitis B. Another possibility is that their status had changed since they were last tested. The authors also describe self assessment of viral status in users never previously tested. The fact that some users guessed wrong may not be surprising.

The authors conclude that "clinicians must be more vigorous in encouraging drug users to reduce risk behaviours." Certainly, communication of harm reduction messages is important and requires sustained effort. There is some encouraging evidence that such messages may have an impact.[4 5]

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Value of screening for hepatitis C is still debatable

EDITOR—Best et al encourage clinicians to test all injecting drug misusers for hepatitis B and hepatitis C as a "catalyst for further intervention."[1] Routine immunisation against hepatitis B in injecting drug misusers is now national policy, and screening for hepatitis B is therefore a sensible first step, but whether to screen for hepatitis C in injecting drug misusers is much more debatable. Best et al have not given their proposal sufficient critical consideration.

When the proposal is examined more critically, serious potential problems are clear. Firstly, it is usually best that an effective and acceptable treatment is available for the condition being screened for. Treatment efficacy itself is only about 40% with dual treatment (which is not currently funded), and the merit of prescribing potentially toxic drugs to patients with disordered lifestyles is unclear. The second potential disadvantage of screening is the probable lack of provision of counselling. Some patients have committed suicide because they were unable to cope with the implications, real or perceived, of the diagnosis. Wider resource implications should also be debated—not least the scale of potential costs. In Sheffield alone there may be around 10 000 injecting drug users. If only half were found to be positive for hepatitis C virus—a very conservative estimate—specialist services would be severely overburdened.

We agree that clinicians must be more vigorous in encouraging drug users to reduce risk behaviours, but screening is not a prerequisite if patients are not suitable for treatment. In view of the potential harms that screening may cause we do not believe, on balance, that clinicians should offer routine screening for hepatitis C until resources for management are available. At the least, a fuller debate is needed nationally and locally before such screening is instituted. The arguments for routine screening will become stronger as more effective treatment emerges, and we welcome the inclusion of dual treatment in the proposed programme of work for the United Kingdom's National Institute for Clinical Effectiveness (NICE).

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Authors' reply

EDITOR—We agree with Ramsay et al about the importance of hepatitis B immunisation.[1] The short report that these letters are commenting on, however, concerned the accuracy of perceptions; hence the issue of immunisation was not discussed, particularly in view of the limitations on word count. The point may be pertinent but does not alter our conclusions.

Judd et al ask about the blood tests that were used. They measured antibodies to hepatitis C and viruses; we did not measure antigens.

The aim of the study was to examine the relation between the drug users' perception of their status and their actual status; we are aware that many of the users' responses would have been guesses. This is not, however, a limitation of the study—indeed it is precisely this point that makes the findings so important. It is the participants' beliefs about their status that will influence their risk taking, not their actual status. Actual status determines risk, but it is belief about status that influences behaviour.

With regard to the final sentence of Judd et al, the reference to "evidence" is, in fact, no more than a reference to their own previous assertions on the topic; it is hence still compatible with the observation of Ramsay et al of the lack of evidence.

The crucial point from our study is that many of our subjects had inaccurate beliefs about their status, particularly those who believed that they were negative when they were, in fact, positive. If Ramsay et al are accurate in their conclusion that knowledge of hepatitis status has little impact on behaviour then this may be of little benefit in terms of prevention. In contrast, if knowledge is associated with behaviour change (as changes in needle sharing after the HIV epidemic suggest) then increasing drug users' knowledge of their hepatitis status has important implications for the prevention effort.

This also challenges the assumption of Suckling et al that treatment for seropositive status can only ever be in the form of a medicine. Education campaigns with injecting drug users after the initial spread of HIV shows that behaviour change is a realistic goal, but it is predicated on education and knowledge. Behaviour change is precisely the "treatment response" that needs to be achieved with educational work and a range of therapeutic approaches with seropositive patients to benefit them, their intimates, and the wider populations. Thus services can promote behaviour changes within the harm reduction paradigm,[2] regardless of pharmacotherapies for hepatitis C.

Finally, the fear that services might be overburdened if patients positive for hepatitis C virus were encouraged to seek an established effective treatment is discriminatory on the grounds of diagnosis. The NHS cannot withhold an effective new treatment simply because its provision would be a burden or because the patient population is unpopular and lacks effective advocacy.

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Acupuncture may be associated with serious adverse events

EDITOR—In their review of acupuncture, Vickers and Zollman[1] state that systemic infection seems to be uncommon. When it occurs, however, it can be devastating, and the single reported fatality from acupuncture last year was due to streptococcal toxic shock-like syndrome.[2] A 41 year old man who received acupuncture for shoulder pain collapsed three days later with rapidly spreading erythematous and necrotic change in the skin of the shoulder. Despite immediate extensive debridement and high doses of antibiotics, he died one day later.

Acupuncture is associated with life threatening complications, although these may well be rare.[3 4] We recently searched the literature available on Medline, Embase, and the Cochrane Library for all reports of serious adverse events associated with acupunc-

Summary of 11 reports of adverse effects of acupuncture reported in 1998

Adverse event (outcome)*	Country	How causality was established	Risk factor identified	Causality	First author†
Streptococcal myositis (fatal)	Japan	Bacteriology	—	Probable	Onizuka
Argyria (persistent)	Austria	Skin biopsy	—	Possible	Legat
Angina, 2 cases	China	Electrocardiography	Scalp electroacupuncture	Definite	Li
Cervical spinal epidural abscess and vertebral osteomyelitis	Japan	Tomography	Diabetes mellitus	Probable	Yazawa
Closed ankle fracture converted to an open fracture	USA	Not stated	—	Probable	Kelsey
Occlusion of popliteal artery (persistent claudication)	Sweden	Angiography	—	Probable	Bergqvist
Pneumothorax	Australia	Chest radiography	—	Probable	Fulde
Pneumothorax	Japan	Needle seen on tomography	Indwelling needle	Definite	Yamaya
Pseudoaneurysm of renal vessels, with rupture	Japan	Angiography	—	Probable	Matsuyama
Septic sacroiliitis	Taiwan	Bone scan, tomography	Poor sterilisation	Probable	Lau
Temporomandibular abscess, *Clostridium* spp	Japan	Bacteriology	Poor sterilisation	Probable	Matsumura

*When no outcome is mentioned, full recovery occurred.
†Reference details on *BMJ*'s website, www.bmj.com

ture which were published during 1998. Eleven case reports were found and are summarised in the table (a complete list of references is available on the *BMJ*'s website).

There were several other cases of infection that ran a severe, prolonged clinical course and required intensive treatment. Accurate diagnosis was often delayed because patients were reluctant to tell their doctors that they had received acupuncture. Angina during electroacupuncture was reported in two patients, an event that has not previously been reported; both cases were confirmed by recurrence of the symptoms on re-exposure.

In addition to these case reports, we found three relevant surveys. A cross sectional survey of seropositivity for hepatitis C in Japan found an increased risk of hepatitis C associated with acupuncture (odds ratio 2.46 in male patients, 1.81 in female patients). A prospective survey of Japanese acupuncture practitioners recorded adverse events during 55 000 treatments. Only 64 adverse events were recorded, the most common being forgotten needles and faintness. A questionnaire survey of 121 consecutive patients given acupuncture in Germany found that 29% reported at least one event during the course of treatment, and adverse events occurred during 9% of treatments, the most common being needle pain (4%).

We conclude that acupuncture continues to be associated with occasional, serious adverse events and fatalities. These events have no geographical limits. Most of these events are due to negligence. Everyone concerned with setting standards, delivering training, and maintaining competence in acupuncture should familiarise themselves with the lessons to be learnt from these untoward events.

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Healthcare providers in New Zealand and England could learn from each other

Editor—In asking what lessons primary care groups can learn from New Zealand's independent practitioner associations Malcolm and Mays seem to be underestimating the opportunities that primary care groups bring and the progress made so far.[1] They correctly state that from April 1999 the chief executive of each NHS trust and the chairperson of each primary care group became accountable not only for the financial health of the organisation but also for the quality of the clinical services it delivers. This is a fundamental change in the delivery of health care in England, which provides an opportunity to change the culture of the NHS.

Through primary care investment plans primary care groups have both an opportunity and an obligation to place quality issues at the centre of primary care development. As primary care groups develop care pathways with providers of secondary care in the process of commissioning they can begin to set standards for secondary care too. Rather than clinical governance being interpreted in a restricted manner that excludes the management of resources, the two areas are inseparable.

The authors suggest that managers and clinicians are reluctant to set priorities in the use of resources. The local health improvement programme inevitably sets targets and priorities. It allows primary care groups to improve the quality of clinical services in areas of particular need for that locality.

Clinical governance is resulting in change, to a culture that emphasises peer review, risk management, significant event analysis, and personal and organisational development.[2 3] The organisation of primary care groups facilitates this change—for example, the appointment of primary care group pharmacists and the development of an infrastructure in information management and technology encourage and support cross practice audit. A similar culture change seems to be taking place in New Zealand, and the lessons learnt could be usefully shared.

Because the financial responsibility of a primary care group is wider than that of an independent practitioner association, the scope for improving the quality of clinical services is also wider. In addition, primary care groups work with agencies such as social services, local councils, and the voluntary sector. This allows them to improve the health of a population rather than be restricted to improving the health care of that population.

Primary care groups are in a far stronger position to deliver clinical governance and have made more progress than perhaps the authors appreciate. Indeed, with the recent change in government in New Zealand, it might be argued that primary care groups could provide a new model of primary care for that country.

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Bible's stance on homosexuality

Bible shows no understanding of homosexual orientation as mutually supportive and affirming

Editor—Wayte quotes selectively from the national survey on sexuality about the prevalence of homosexuality.[1] He is doing exactly what I reported in my personal view—distorting the evidence.

He says that the "Bible references to homosexuality clearly show that they are disapproving of homosexual activity (not orientation)."[1] Experts in biblical interpretation believe that in biblical times there was no understanding of the modern view of homosexual orientation as mutually supportive and affirming.[2 3] Wayte is right in saying that the Bible's stance is not to "bash homosexuals." Leviticus chapter 20, verse 13 reads: "If a man has intercourse with a

man as with a woman, both commit an abomination. They must be put to death." So the Bible's stance is not just to bash homosexuals but to murder them. Why Wayte or anyone else wants to associate themselves with such barbarous and inhuman texts is beyond my comprehension.

Wayte comments on the medical risks of homosexual activity by which he presumably means anal intercourse. But only two thirds of gay men take part in anal intercourse while as many as one third of heterosexuals do so. This means that more heterosexuals than homosexuals have anal intercourse.[4] Wayte's criticisms should therefore be primarily addressed to heterosexuals. And the national survey found that there is no great disparity between numbers of partners overall.

Wayte says that the use of the word homophobia in this context is incorrect. A recent survey of 4000 known homosexuals and bisexuals has shown that 34% of gay men and 24% of lesbians had experienced physical violence and 73% had been taunted in the previous five years because of their sexuality.[5] This is clear evidence of the "extreme abnormal fear or aversion to" homosexuality which Wayte rightly quotes as a correct (though ungrammatical) definition of homophobia.

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1 Wayte C. Bible is disapproving of homosexual activity but not homosexual orientation. *BMJ* 1999;319:123. (10 July.)
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Summary of rapid responses

We received 12 responses to the letter by Wayte replying to Shearer's personal view that some Christian documents misrepresent the sources they quote.[1] Only one response from the 11 respondents (seven of whom declared themselves to be gay) was supportive of Wayte's position. The rest were highly critical of Wayte's thesis and of the *BMJ* for publishing his letter.

"What the Bible has to say about homosexuality is of no interest in a scientific discussion, but Wayte's claim that the Bible is 'disapproving of homosexuality . . . to protect people from dangerous behaviour'—that is, HIV infection—is fanciful in the extreme, given that the authors of the Bible cannot have had knowledge of HIV" (P Bailey).

"I had no idea that the Bible was written in the early 1980s in response to the AIDS crisis . . . . I am not sure of the figures for young people unable to reconcile their sexuality and their faith who harm or kill themselves each year but I hardly think the Bible's stance assists these people either" (P Barron).

Having studied the experiences of gay and bisexual men in primary care, B Cant defines the existence of homoscepticism—"a lack of awareness of gay social networks and a lack of appreciation of the values, connections and desires that bind these networks together." He argues that it is "preventing gay men from getting the primary health care they need." J S Dawson adds: "Whether the Church condones such activity or not is irrelevant, we as health professionals should remain impartial and eager to offer help and advice to whoever, whatever their sexual orientation."

Respondents were not only sceptical about the relevance of the Bible to health matters but also puzzled by the *BMJ* publishing Bible based medicine. G Rimar begins: "It surprises me that a medical journal sees fit to discuss health issues from a biblical perspective," while K C Crosby ends declaring his competing interest as "the overriding belief that theological debates have no place in medical science." C Ward concludes: "In an era when we are supposed to be practising evidence based medicine I am surprised to see the Bible in the reference list."

1 Electronic responses. Bible is disapproving of homosexual activity but not homosexual orientation. *eBMJ* 1999;319 (www.bmj.com/cgi/eletters/319/7202/123/b). (Accessed 8 December.)

Evidence produced in evidence based medicine needs to be relevant

Editor—It was encouraging to see all the research papers on patient involvement in healthcare decision making in the issue of the *BMJ* on 18 September devoted to patient partnership. Research findings in this area go some way to filling the enormous gap in evidence that has existed for too long. There are publications that offer guidance on how to involve patients and the public, but these give practical advice and do not detail the evidence of these approaches.[1]

This emergence of evidence is particularly timely given that the importance of patient and public involvement has been emphasised throughout government policies. Evidence relevant to patient/public involvement in clinical governance, health improvement plans, the development of primary care groups, and more recently the public health white paper *Saving Lives: Our Healthier Nation* is much needed.[2] As the momentum of research in this area is beginning to build up we would suggest that there may be some lessons to be learnt from clinical effectiveness evidence.

Simply having evidence available will not necessarily mean that it will be used. Like many clinicians in the case of evidence based medicine, those who need the evidence on involvement of patients may not have the motivation to access it via scientific journals or the skills to appraise it. Accessibility through appropriate presentation and dissemination is therefore an important consideration. Additionally, as found with clinical effectiveness evidence, to be of real value and to get used the evidence produced must be relevant to those working in the field.[3 4] This means that research should try to answer questions that such people want answers to and not simply cover topics that are interesting or can be researched using the methods deemed "fundable."[5]

From the Office for Public Management's perspective (the office is an organisation that supports NHS bodies involving patients and the public in decisions), an increase in the evidence base of approaches is greatly welcomed. An important consideration for those who will produce the evidence, however, is that its impact will depend on how relevant it is to the NHS agenda and how accessible it is to those in the field.

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Fatigue and psychological distress

Statistics are improbable

Editor—Although this paper by Pawlikowska et al is nearly six years old, I read it only two months ago.[1] I am surprised that there seem to be no letters or articles referring to it to point out that the analysis is flawed.

The authors report results from a general health questionnaire on a scale of 0 to 36. They provide a histogram for the distribution, which has a mean close to 14. The authors quote the mean scores for men and women as 24.7 and 26.2 respectively. They give confidence intervals for these means and for the difference between them. These means are both above the 90th centile of the distribution of general health questionnaire score that they show. They are clearly impossible.

Their fatigue score is also shown as a histogram. Possible values for observations are between 0 and 33, and the mean is also about 14. The means for men and women are quoted as 24.1 and 25.2, both of which seem to above the 95th centile. Again, they are clearly impossible.

There are several more subtle statistical problems: the histograms with unequal interval sizes shown as the same length on the graph; the statement that with such large numbers the distributions of responses to the fatigue and the general health questionnaires follow a normal distribution (the shape of the distribution is not related to the sample size); the ignoring of the cluster sampling; the use of two different scoring systems for the questionnaires. But the quoting of impossible means should be enough to show that this paper is flawed. Why has

nobody noticed, in refereeing, editing, reading the paper (several authors have cited it but seem to accept it uncritically)?

Although two people are acknowledged for help with computing, nobody is acknowledged for help with statistics. The authors used SPSS. Did they include a missing data code without declaring it? A few 999s would produce the means they quote. Does this problem run through all the calculations?

I think the authors should be asked to explain this and, if necessary, carry out a reanalysis, with competent statistical advice. Potentially incorrect conclusions, based on faulty analysis, should not be allowed to remain in the literature to be cited uncritically by others.

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1 Pawlikowska T, Chalder T, Hirsch SR, Wallace P, Wright DJM, Wesley SC. Population based study of fatigue and psychological distress. *BMJ* 1994;308:763-6.

Authors' reply

Editor—Bland is, of course, correct, The means quoted in our 1994 paper are incompatible with the graphs presented. Our first thought was that this is related to the many and confusing ways of scoring the general health questionnaire and that we used two different scoring systems for the graphs and the analysis. This was, however, not the case. On returning to the original analysis and printouts, the means are quoted correctly. Somewhere between the analysis and the printed copy we have been attacked by gremlins.

Sadly, the passage of time, theft of a computer containing the original draft, and the fact that none of us can find the proofs anymore, mean that we have no idea when this happened. Like Professor Bland, we find it hard to believe that the usually infallible statistical reviewers at the *BMJ* could have overlooked this and wonder, totally ungallantly, if we can transfer the blame to the production side. We will probably never know.

For the record, the correct values are (original printouts available from us on request):

The mean Likert score for the general health questionnaire was 13.58 (95% confidence interval 13.48 to 13.69); in men 12.74 (12.58 to 12.89); in women 14.22 (14.08 to 14.36).

The mean Likert score for fatigue was 13.72 (95% confidence interval 13.65 to 13.79); in men 13.13 (13.03 to 13.24); in women 14.16 (14.06 to 14.25).

Nothing else in the paper has changed in any way, including the figures, and the conclusions are unaltered. We thank Bland for bringing this to our attention.

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Evaluation of effect of changes is essential in policymaking

Editor—Dixon and Preker summarise the recent broad trends in reform of international health systems, arguing that the current NHS reforms represent an addition to the debate about public versus private provision.[1] In this regard, they see the NHS as an important test bed. We think that two points should be made.

Firstly, entire health systems should not be used as test beds. Recent experience in the NHS has shown that governments are willing to implement untried reforms for the sake of political expediency. But this need not be the case: reforms can be the subject of pilot studies or modelling. The current government has signalled an intention of increased piloting of new service structures[2] and has introduced pilots of general practice commissioning groups, personal medical services, and personal dental services. Despite this the approach seems to be piecemeal and applied only to initiatives at the margins of health policy. More fundamental service changes, such as the proposed introduction of primary care trusts, remain untested yet destined to have major impacts on the NHS.

Secondly, once reform is implemented, its effects should be carefully and independently evaluated. Health reform produces complex and sometimes subtle changes in practice and outcomes, which cannot be reliably evaluated with ad hoc studies based on crude measures such as activity. Prospective studies, which do not rely wholly on routinely collected data, should be seen as an integral part of the health reform process.

The Department of Health should increase its funding of policy evaluation and accept the need for independent evaluation of health reforms. Experimentation without evaluation is not acceptable in medicine, nor should it be in policymaking.

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1 Dixon J, Preker A. Learning from the NHS. *BMJ* 1999;319:1449-50. (4 December.)
2 NHS Executive. *GP commissioning groups.* Leeds: NHSE, 1997. (EL(97)37.)

⁂Details of the conference "Learning from the NHS," on 3-5 April 2000, are available from Jane Lewis (jlewis@bma.org.uk).

Getting HIV/AIDS accepted on the political agenda

Editor—The editorial by Nicoll and Godfrey-Fausett points out that Commonwealth countries have a disproportionate burden of the HIV and tuberculosis epidemics.[1] Of the eight countries with the highest prevalences of HIV, seven—Botswana, Lesotho, Malawi, Zimbabwe, Zambia, South Africa, and Swaziland[2]—are members of the Commonwealth. In none of these countries is the HIV epidemic recognised at the highest government level, despite the predictions, now being borne out, that illness and mortality associated with HIV will be a considerable drain on their economies. Without the political will to encourage HIV prevention activities, the AIDS epidemic will continue to be seen as just another health problem in competition for resources with other divisions of the health sector.

The Commonwealth and the Association of Commonwealth Universities could have an important role in getting HIV/AIDS accepted on the political agenda. The political leaders of all these countries are men. Most infected women in Africa are infected by their only sexual partner.

Clearly there is a need to focus on men, but most national and international agencies, including the Department for International Development, seem to be targeting women.[3] The male government leaders must be persuaded to put across the message that men should accept responsibility for the epidemic in a manner appropriate, acceptable, and relevant to their own cultures, as has happened in Uganda. As well as targeting tuberculosis, countries in the Commonwealth worst affected by HIV also need to recognise the importance of sexually transmitted infections in facilitating HIV transmission and to develop a more focused and technical approach than that adopted hitherto. In all the countries worst affected by HIV, there is a high prevalence of genital ulcer diseases. By contrast, in other Commonwealth countries—for example, Ghana, Nigeria, and Sierra Leone—where HIV is not such a significant healthcare problem, genital ulcers are a minor problem.

Technical expertise in sexually transmitted infections in most African countries is still minimal. Few doctors either specialise or have an interest in the subject. In these worst affected countries HIV infection should clearly now be made a special case. One short term answer might be for the Commonwealth to sponsor retired specialists in sexually transmitted infection, or for those in the training grades in the North, to be seconded to these worst affected areas. Open discussion through the Commonwealth forum could be a major stimulus to promote HIV awareness and also to promote the limited success stories in HIV prevention in Africa so far.

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1 Nicoll A, Godfrey-Fausett P. HIV and tuberculosis in the Commonwealth. *BMJ* 1999;319:1086. (23 October.)
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3 Department for International Development. Reproductive and sexual health. *International Health Matters.* 1999;No 4. (June issue.)